



651 E. 159th Place
South Holland, IL 60473
708-331-7370 Telephone - 708-339-5423 Fax - www.FamilySupportNetwork.org

Health & Medicine Policy Research Group
29 E. Madison Suite 602
Chicago, Illinois 60602-4404

November 22, 2013

Dear Sir/Madam:

Thank you for the opportunity for The Family Support Network (FSN) to share our recommendations on the goals and strategies of the Illinois Medicaid 1115 Waiver. The FSN represents families and individuals throughout the state of Illinois with intellectual and other developmental disabilities (I/DD). The Family Support Network further seeks to ensure the continuation of all individual supports as needed throughout the lifespan of the individual. We strive to provide access to supports and services that are easy to find and easy to use.

Based on the information that has been currently provided, we are not clear as to how this Medicaid Transformation 1115 Waiver will change the way services will be administered, especially to persons with I/DD, and how it will impact the capacity and quality of our community services.

FSN offers the following recommendations for the 1115 Waiver and we strongly endorse the need for flexible supports/services offered in community settings which include interaction with non-disabled individuals.

Sincerely,

Shirley A. Perez

Shirley A. Perez, Executive Director

HOME AND COMMUNITY BASED INFRASTRUCTURE, COORDINATION AND CHOICE

Key Points in Flexible Service Options

Individualized Budget

- Flexible services will be part of an overall individualized budget that can be used to fund supports/services as needed for a person throughout a 24-hour day/365 days a year.
- An individual's plan will include a budget for additional funding as needed.
- Additional Direct Support Person (DSP) as needed for specific activities, opportunities, job support, etc.
- Transportation will be separated from CILA budgets. Funding may be provided on an individual basis, which could include mass transit access or operation of personal vehicles.
- Offer a full array of service options that promote competitive employment, person-centered and self- or family-directed services, and services offered in natural environments that are typically used by non-disabled peers.
- Costs for participation in programs and classes not covered by Medicaid (if the person lives in their own home, funds will not be controlled by the provider and a larger amount could potentially be budgeted for personal expenditures. Budgeting assistance will be given to the individual to make sure living expenses are met.)
- Transportation will not be tied to the services offered unless needed.
- Medication should be administered (as prescribed) in any setting so that people are not restricted in their activities or service option locations due to medication needs.

- All services will be distinctly separate from the settings where they are provided. An individual will be able to choose self-directed or agency-based services regardless of whether they live in the family home, their own home, or an agency-based home.

Examples of Flexible Service Options

- 1). Alternatives to traditional day training (“sheltered workshops”) and other supports:
 - a. Employment – embracing the tenets of “employment first”
 - b. Community activities – which might include volunteer work, social activities, education, leisure activities, personal fulfillment activities of the individual’s choice.
 - c. Housing – in-home CILA, individually owned/controlled home supported by contract with provider, intermittent services etc.
 - d. Personal Networks – Personal Networks refer to a set of human contacts known to an individual, with whom that individual would expect to interact at intervals and to support a given set of activities, who are not employed by the provider agency. This network should include a Qualified Intellectual Disabilities Professional (QIDP). QIDP must have at least one year of experience working directly with people with developmental disabilities and meet the minimum federal educational requirements for a QIDP outlined in 42 CFR 483.430.
<http://www.dhs.state.il.us/page.aspx?item=48211>) This network should also include a Service Facilitator (separate service facilitator from provider) who would be responsible for the day-to-day oversight and administration of the service plan and for ensuring the health, safety and welfare of the individual.

(2). Person Centered Plan: Individuals who select non-traditional services will have a facilitated person centered plan to determine their hopes and dreams, as well as needs, supported by identified, measurable goals, identified assets, obstacles, and action plans. It includes specific actions to build relationships with other community organizations/associations and to create natural supports within inclusive community activities/settings. The entire focus, of course, is on the person him/herself, and the plan is completely under the direction of the person and/or his or her representative.

GENERAL COMMENTS

There are two thoughts I would like to conclude with.

1). We need to ensure that all of the stakeholders currently served are represented and no one falls through the cracks.

2). A framework needs to be created to ensure that the input of stakeholders – people with I/DD and their families – is continually sought and continues to inform the course of this transformation.